

# AHS Integration Efforts Autism Planning for the Future

Meeting Minutes

**Date:** Friday, April 29, 2022

9:00-10:30

**Overall Goal of our work group:** How do we use our collective resources to move autism services forward for children and their families in Vermont?

**Strategic Plan Goals:**

- A. To challenge and advise the current system to identify creative, collaborative, and flexible strategies to deliver family-centered care throughout a child’s journey from early identification and diagnosis through adult services.
- B. Increase access to assessments, supports and services up and through transition to adulthood.
- C. Educate community about inclusion and neurodiversity.

**Present:** Cheryle Wilcox, Molly Bumpas, Ilisa Stalberg, Beth Forbes, Jeremiah Dickerson, Nora Sabo, Valerie Wood, Alyssa Heillbrun, Gretchen Pileggi, Paula Reynolds, Cammie Naylor, Phillip Eller, Hillary Hill, Danielle Dukette, Kathy Workman, Adam Poulin, Marinell Newton, Melanie Hall, Rachel Wassell, Erin Russell, Liliane Savard, Cortney Keene, Kelsey Naro, Danielle Briar, Jamie Rainville, Michael Hoffnung, Evie Spratt, Keith Williams

Which strategic plan goal does this tie to?	Agenda Item	Discussion Notes
A. Increase access to assessments, supports and services up and through transition to adulthood.	Joined by Ilisa Stahlberg and Adam Poulin, Vermont Department of Health to discuss developmental assessment work	Ilisa Stalberg: Director of Maternal Child Health. The history of CDC (Child Development Clinic) has shifted for many years, primarily has been driven by federal funding and directed to move out of providing direct service. Other specialty clinics transferred in last 7/8 years to UVMHC. Worked w/Autism Assessment Clinic and UVM to recruit Dr. Forbes, Developmental Behavioral Pediatrician. Vermont has lost pediatric expertise through retirement, etc. In 2018 the CDC moved to hub model – Barre, Rutland, Burlington. Then COVID hit – had to take a pause. When staff could resume regular roles post-COVID and retirement of Dr. Hassler was announced – felt it was time to make a shift. Made announcement in March 2021 that CDC would close. Stopped referrals in late 2020. All referrals went to central intake at UVMHC.

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		<p>Acknowledges this leaves a gap. We are working hard to ensure this doesn't leave kids and families without the dx/info they need. We are hopeful to develop a plan to support families and the system. Recognize lengthy waiting lists.</p> <p>Adam Poulin: Children with Special Health Needs:          Acknowledges significant wait lists and how hard current assessors are working. Current project: build partnerships with VCHIP and medical providers. Survey work – reaching out to folks across the state for input. Looked at different assessment models. Small workgroup convened.</p> <p>Recommendations from this group:</p> <ul style="list-style-type: none"> <li>• Focus increase access to assessments, how build capacity, CSHN/AHS project.</li> <li>• Maximize folks who can do ADOS through medical homes or CIS teams. Identify who is ideal to be trained.</li> <li>• Which regions are best to pilot this model?</li> </ul> <p><b>Discussion points:</b></p> <ul style="list-style-type: none"> <li>• At what point to you bring in clinical expertise to these discussions? UVMMC assessment team is eager to join these conversations. Important to this discussion. Some pediatricians are not comfortable providing even provisional diagnosis. This is a very dynamic process and in early stages – open to discussions.</li> <li>• Is there understanding of what services require what level of diagnostic assessment? Question of small group AHS/CSHN. Sees opportunities for more effective communication about service options.</li> <li>• Consideration of what first tier evals look like – goes beyond just training in the ADOS- clinical expertise is required.</li> <li>• Think about the seats we sit in – how can we elevate the need? Think about this as a group.</li> </ul>

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		<ul style="list-style-type: none"> <li>Recognize Nora and Kathy as mainstays of CDC and the years of dedication they have shown to families and children in Vermont.</li> <li>Danielle Dukette’s small workgroup regarding CIS and ASD training – update – Keith – procuring modest scale model that would offer money for agency to support referral work to cut down on wait time. Will share at future meeting.</li> </ul>
<p>During updates, consider our goals and updates that may tie directly to them.</p>	<p>Phillip – VT Autism Task Force: Autism Acceptance Month, website has lots of information</p> <p>Liliane – ARC – PCORI grants – both of our proposals have passed. Transition from pediatric to adult health care. Feb/March 2023. Building capacity for autism research where autistics are research partners. Importance of elevating autistic voices.</p> <p>Discussion of weight of the wait lists – at least a year at UVM/DB Peds, wait for early intervention services common.</p> <p>Valerie Wood – parent perspective on waiting for diagnosis and services. What services could be made available to families prior to diagnosis? There are stressors on every part of the system right now.</p> <p>Cammie – children who show evidence of a disability should not be waiting for ASD eval for a higher level of service (IEP). If that is happening, have families call VT Legal Aid.</p> <p>Danielle Brier – ABA benefit VT Medicaid can authorize services up to 21 who has ASD dx or early developmental dx.</p> <p>Michael Hoffnung (UVMMMC)– early developmental dx include ADHD, anxiety? Need ABA provider to do assessments and see if appropriate. VT Medicaid would do a clinical review.</p> <p>Erin, Green Mountain Behavioral Consulting – front line staff require lots of training, difficulty finding and keeping them.</p> <p>Courtney Keene (Keene Perspectives) – staffing issues, hard conversations with parents about not having staff to see child. Hard retaining staff due to pay and recruiting staff into the field. Would like to talk to others across the state about this issue.</p>	

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	<p>Liliane – what’s the role of CIS in this – silo providers in the state. CIS need more funding. Work together at interprofessional teaming and care.</p> <p>Update from Vermont Family Network for inclusion in notes—Jamie sent this information after our meeting: Please remember the Parent to Parent support that VFN can offer. You can provide the VFN number so families can call and connect with us. Even if it is just emotional support. We have a number of trained support parents that we can connect families to specific to ASD, but as you know, we are all parents ourselves of a child with a disability. Also, we can help to find resources as well. You can read more here on our <a href="#">website</a> in the Parent Match tab.</p>	
<p><b>Upcoming agenda items:</b></p> <ol style="list-style-type: none"> <li>1. Overview of CANS (Child and Adolescent Needs and Strengths) possible Autism Module</li> <li>2. Special Ed rule changes</li> <li>3. Whose voices are missing from this table? How do we solicit their feedback even if they can’t come to the meetings (e.g. survey)?</li> </ol>		